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ABSTRACT

Issues involved in medical treatment and health promotion among severely handicapped students are addressed. The need for general health care and promotion within this population is stressed, with attention to nutrition, physical activity, and hygiene. Medical issues identified by parents of young severely handicapped children included lack of related support services, needs for parent support mechanisms, provision of alternatives to institutionalization, lack of trained staff, and needs for assertiveness among parents. The importance of coordination of medical services is emphasized as is the elimination of conflicts between medical and educational personnel. Involvement of medical and health disciplines in the educational team is discussed, and guidelines are suggested for what parents should request of medical personnel in terms of attitudes and information. Actions are further suggested to help parents coordinate medical services. (CL)

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Meyer Children's Rehabilitation Institute/University of Nebraska Medical Center

MEDICAL ISSUES IN THE EDUCATION AND CARE OF CHILDREN REQUIRING EXTENSIVE SPECIAL EDUCATION PROGRAMMING

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This paper represents the opinions of the author and not necessarily that of Meyer Children's Rehabilitation Institute of the University of Nebraska Medical Center.

Medical Issues in the Education and Care of Children Requiring Extensive Special Education Programming

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The purposes of this paper on Medical Issues in the context of the proceedings of the National Parent Conference on Education of Children Requiring Extensive Special Education Programming are: (1) description of the need for addressing general health care; (2) exposition of medical issues as defined by parent participants in the conference; (3) identification of disciplines and roles involved in addressing Medical Issues, and (4) proposal of some guidelines for what parents should expect of professionals and what parents can do themselves to address the concerns raised regarding Medical Issues.

In this context "Medical Issues" are interpreted to include treatment needs,the management of acute and chronic health problems, and of equal importance promotion of health and problem anticipation and prevention among severely handicapped students. Also within the context of medical care comes authorization for care and treatment plans for nursing, physical therapy and in some states occupational therapy. While serving as members of educational teams as well as while serving as members of health care teams, medical personnel must consider the student's general health, any health problems presented by the disabilities of the student, nutrition, dental care, management of medication, and the emotional and psychological impact of medical interventions. Consideration of all these issues or factors needs to occur in the development of an I.E.P.

Need for General Health Care and Promotion

Education of severely handicapped students of all ages has presented unique challenges to school systems. Child development experts, whether they be from educational or medically oriented fields, have always preached the importance of care of the "total" child. Education administrators generally have been able to feel they have been faithful to that dictum through rather standard school health programs such as general vision and hearing screening programs, a school nurse available to treat acute problems, and the provision of hygiene classes. Similarly, medical professionals have been able to attend to acute care and health promotion of children without intruding to a great extent upon the educators domain. Each general area, medicine and education, has been able to provide within its own domain of expertise and responsibility with little need for accommodation of one to the other until the advent of the federal legislation PL 94-142 mandating the Education of all Handicapped students.

Such separate worlds are not possible if the severely handicapped student is to receive an appropriate educational program. Areas of medical/health concern which must be addressed in the educational plan for a severely handicapped student include: nutrition, medication, ongoing appraisal of sensory systems, dental care, assessment of bone, joint and muscle alignment, deformity prevention, special disability related problems, and maintenance of general hygiene. These are, of course, areas of health and medical concern that must be addressed for all students whether handicapped or nonhandicapped. With severely handicapped students, however, attention to these issues becomes more complex. In this regard it is assumed that good health is a prerequisite state for one to derive optimum benefit from an educational program. Several

of these areas will be discussed in more detail in an effort to clarify this point.

Nutritional needs for calories and balance among nutrients are generally determined by age, stage in life, and size. Educators with advice from nutritionists have long recognized this and, for example, have incorporated snacks breaks into the daily routine for preschool and primary grade children. However, many severely handicapped children have great difficulty ingesting food because of physical disabilities. Some may need many more frequent feedings of small amounts at a time. Many of these students also cannot request liquid when they are thirsty. Adequate food and fluid intake is essential for maintenance of health and prevention of secondary problems. It may be necessary to stipulate the minimum number of times that fluid and food should be offered during the school day within a student's IEP if a given student is to optimally benefit from an educational program.

Physical activity and movement are essential to our maintenance of an alert state. This principle has long been recognized by educators. Students with physical handicaps, in addition to decreased mobility, may have decreased sensation and awareness of the position of their body parts. Specification of the minimum number of and frequency of assisted position changes during the course of a school day should also be addressed in the student's Individual Educational Plan. Such position changes can be instrumental in preventing breakdown of skin and muscle tissue, prevention of muscle and joint deformities, and as a positive force provide an increased level of awareness of the environment on the part of the student.

Maintenance of good hygiene is a critical need for the individual student's well being and to enhance acceptance of the student by other

individuals in the environment. Maintenance of good hygiene is not fostered effectively among severely handicapped students (nor for any student) by posters on the classroom walls. Good hygiene practices must be an ongoing part of the daily educational routine.

These examples have been purposely selected because the author feels that medical issues regarding the education of the severely handicapped have been too narrowly interpreted as the related services of physical and occupational therapy.

Still another medically related issue is the psychological impact of special therapies or health related treatments. It is not sufficient to design intervention and make them available. Overall health promotion requires that those interventions be designed and modified as necessary to accomplish active cooperation by the recipient of the treatment (figuratively, "A spoonful of sugar," if you will).

Medical and Medically Related Issues Identified by Parents

Parents' initial confrontation with the fact that they have a handicapped child is likely to come from a physician. For severely handicapped persons, that confrontation for the parent probably occurred in the first months or years of the child's life. The group of parents who chose to discuss Medical Issues at the National Parent Conference on Education of Children Requiring Extensive Special Education Programming were parents of children under five years of age. The Medical Issues identified by them were concerns around the manner in which they were initially informed of their child's diagnosis and models of early intervention. A number of the issues identified could be discussed, and indeed will be discussed under other topics identified for this conference, particularly the topic of emotional issues. Such repetition is, in the author's opinion, acceptable and even desirable. As more parents feel

free to speak out, it becomes more apparent that the manner in which the news of a handicapping condition in their child is presented to parents greatly affects the energy a family has available for coping with and accepting both the child and his or her diagnosis.

Lack of related services:

Parents in the group expressed concern that many of the services recommended for their child were not available to them. For the most part the related services identified were physical and occupational therapy, and educators with specialized training in interventions for students with sensory impairments. In discussion of this issue several points were made including: the need for access to information regarding what the related services could and could not accomplish; agencies responsible for providing the services; the shortage of related services personnel qualified to provide the services in many parts of the country.

Parent Support Groups:

Parents in the discussion group were unanimous in identifying the need for parent support groups as one of the most helpful mechanisms for coping with the day to day issues they face in caring for their child. Parents at the conference emphasized a point made frequently by many parents. That is, the functions of parent support groups are two fold: (1) to receive useful information and support; (2) to provide an opportunity to offer information and support to others, thus increasing their own feelings of self worth.

Alternatives to institutionalization:

Identification of the need for alternatives to institutionalization provoked considerable discussion in the group. Anger was expressed about recommendations to institutionalize their children. Anger was also expressed about the fact that there seems to be little agency support for occasional

relief care which would obviate the institutionalization of a young severely handicapped child. Parents are placed in a dilemma. Many do not want institutionalization particularly at a very early age because of an intuitive knowledge of what separation does to emotional ties. They also recognize that institutional care is costly and taxpayers bear that cost. Yet there are disincentives for less costly alternatives or they are not available. The recent case of a three- year- old child in an Iowa hospital is unfortunately not unique. The parents of this child wished to bring their daughter home. The care she would need cost about $1000 a month for home care compared to $3000 a month for hospital care. However, there were resources for payment for hospital care but not for home care. The government waived those regulations for this one case, permitting the family to receive the medical assistance for home care. Cases such as this probably occur more frequently than we would like to recognize.

Lack of Trained Staff:

Several parents identified the lack of adequately trained professionals as an issue. Further discussion centered on the point that in many cases there was a lack of personnel, but in some cases available personnel have not received adequate preparation in addressing the specific problems and concerns of parents of handicapped children. Again, quite appropriate anger was expressed about lack of sensitivity to parental needs and the tendency to devalue parents' contribution to the raising of their children. With respect to medicine these comments on a "lack of sensitivity" centered around an emphasis placed upon the facts and details of a diagnosis rather than on the uniqueness of the child in his or her family (Dougan, Isabel, and Vyas, 1979); a lack of opportunity to ask questions, a discounting of fears and concerns,

and a failure to involve parents in the care planning and problem solving processes.

Another tendency among professionals (not just physicians) that is an irritant to many parents is the labeling of parents' reactions with terms that were initially developed as descriptions of stages of adjustment. These terms have come to be used as value judgments and "put downs." Such terms include overprotection, denial, rejection. These terms have been reified and the minimal damage their use does is to block communication. In some instances the unthoughful use of terms such as "overprotective" or "not accepting well" has possibly done damage to already vulnerable feelings of selfworth. Basic tenents of counseling seem to be forgotten by many professionals when they are working with parents of handicapped children including: (1) providing information to make decisions, but not making them for clients; (2) not making judgements based upon one's own anticipation of how one would feel if faced with a given situation; (3) recognition on the part of professionals when they are so involved so as to be passing judgement in a case.

Parents Need to be Assertive:

A pervasive tone of the discussions at this conference was that parents were willing to share in the responsibility for how they were treated. The same parents who expressed anger about the ways in which professionals had dealt with them were also able to say that they, the parents, were the people who could change those attitudes in the future. The point was made that parents need to find out what they and their child's rights are, and they must develop skill in asserting themselves in obtaining those rights. In the context of this discussion one father pointed out that he "had fired" a physician whom he felt was not open to his wife's and his input regarding their daughter. A paper distributed by the New Hampshire Parent Information

Center conveys the tone of the discussion on parents' needs to be assertive and the previous topic of professional attitudes.

"The key to change lies in a new look at old roles. It means seeing professionals - not as many parents have seen them in the past, as awesome and inaccessible pedestals - but as people with whom an ongoing dialogue is possible. It means that more professionals must start listening, really listening, to what parents are saying, for in this role parents are the teachers, experts on what they themselves experience, feel and need" (New Hampshire, PIC).

Need for Coordination of Medical Services

The parents in this group at the conference identified a lack of coordination among professionals responsible for different aspects of their child's care as a primary problem for them. In other situations I have heard parents make similiar complaints. At an Academy of Cerebral Palsy Workshop on Management of Cerebral Palsy, a parent of a young boy who has cerebral palsy and is deaf commented that one professional left off the team that worked with him, his wife, and their son was a time management expert. The number of demands placed upon parents and a child's time for different aspects of therapy can be overwhelming, particularly if the parent and various professionals only meet together as a group every three to four months. One mother told me a few years ago that while all the individual therapy services her son received at our center were excellent, they were all separate and she identified the missing ingredient of the services as "glue." I would add to her point that while she quite capably integrated all those diverse inputs, she should have received more help in accomplishing that task.

Another aspect of coordination of services that was discussed was the timing of medical treatments, especially those that will be incapacitating for

a time. For example, some of the surgeries that are recommended for physically handicapped children are procedures that could be timed to coincide with school breaks so as not to interrupt already shortened school schedules. This is just one example of an area in which children and their families would benefit from coordinated planning between education and medical professionals.

Conflict between Medical and Education Personnel:

Several parents expressed concern that they felt that they and their children were in the middle of conflicts between the medical and educational professionals who were working with their children. The conflict most often described by parents relates not to the specifics of their child's Individual Educational Plan but whether the professionals involved accept the fact that federal law has mandated a free appropriate educational program for all children despite the degree of handicap. There are many education administrators and even more physicians who philosophically cannot accept the current programs for severely handicapped as fitting their definitions of education. Parents who persist in advocating for services for their children are subjected to the following arguments: (1) during a time of decreasing economic resources it is unfair for parents of severely handicapped children to demand programs for their children; (2) this is especially so for a child who will show only limited progress; (3) it is unfair to other family members, particularly other children, for parents to invest time and energy into the care of a severely handicapped child. Obviously these professionals, no matter what their field, are entitled to a philosophical opinion regarding services for severely handicapped persons. However, it is not appropriate that a doctor-patient, therapist-client relationship or an educator-taxpayer/parent relationship be used as the context for expression of those opinions in the guise of professional guidance.

For example, let us examine the basis for the argument that keeping a severely handicapped child at home is damaging to other family members. A recommendation for institutionalization is most likely to be made to a family by a physician and the most often cited rationale is that the child is so demanding of time and other resources that other children and the marital relationship will suffer. Many of us, whether drawing upon our professional or private experience, can think of situations where indeed this argument seems to hold. However, when looked at as a whole the data on the subject of the effect of a handicapped sibling upon other family members are equivocal. Siblings report both positive and negative feelings about being raised with a handicapped sibling. Spouses report both positive and negative aspects of keeping a handicapped child in their home. Also, most of the data available on this subject are based upon the experience of parents of severely handicapped persons who were born one, two or three decades ago, during times when services were much more limited and attitudes and acceptance of handicapped persons within the community were different than presently exist. The issue of placing a child outside the biological home for care is not one where there is a universally appropriate recommendation. Professionals need to recognize the tenuous knowledge base upon which such a recommendation rests and evaluate their own recommendations and the context in which they make those recommendations.

Need for Increased Knowledge on the Part of the General Public:

In our discussion group the parents were unanimous in their opinion that the general public should be exposed to more information regarding the nature and causes of handicapping conditions and the need for and effectiveness of services for handicapped persons and their families.

General Health Care and Health Promotion:

Generally, Pediatricians view one of their roles as the overall health management and health promotion of the children that they serve. The increasing emphasis placed on care of handicapped children by specialists in medicine (pediatric neurology, developmental pediatrics, orthopedics, psychiatry, ophthalmology etc.) and allied health specialists such as physical, occupational, and developmental therapies, has resulted in an underemphasis upon overall health management and ambiguity as to which member of the team is going to supervise the general health management and promotion. According to Bennett (1982) "the pediatrician has two unique functions and responsibilities when participating in the interdisciplinary evaluation of a child with developmental/behavior problems." The first of those unique roles is to "assess the medical status of the child and determine what, if any, influence the child's overall health is having on his or her developmental course (p 309)." Included in that initial assessment at the time of identification of a problem and in ongoing management of the child are evaluations of growth, review of development of systems such as cardiopulmonary, digestive nutritional status, effect of chronic medications, immunization status; vision and auditory functions and frequency and severity of acute illnesses. As emphasis is placed upon specific therapies, this ongoing review of health status and interventions to promote health sometimes assumes secondary status among the priorities of the disciplines working with the child. Even coordinated management by an interdisciplinary team is prey to this problem of overlooking general health status, and the daily interventions that would promote such health status.

Health Disciplines Participating in the Educational Team:

Provision of medically related services under PL 94-142 has generally resulted in an emphasis upon the provision of physical and occupational therapy for students with physical handicaps. Again, we can see the tendency to compartmentalize the child and emphasize a disability sometimes to the neglect of the total child. While a given discipline may have more extensive input on a particular child at a given time, the person from that discipline needs input from all health related disciplines to adequately attend to health related needs in the development of a student's IEP. These disciplines include medical subspecialities of pediatrics, neurology, orthopedics, ophthalmology, psychiatry, ENT and nursing (especially preparation in maternal-child health nursing, or medical care of chronic conditions in children), nutrition, clinical pharmacology, in addition to physical and occupational therapy. It is not practical that all of these individuals be members of the IEP team. However, the points of view and domains of expertise each represents need to be incorporated into the overall design of educational intervention for students with severe and multiple handicaps.

Primary Care and Consultation Roles in Health Promotion and Medical Care

The management of children with complex and severe disabilities, including initial diagnosis, ongoing intervention and evaluation of interventions, requires involvement of all health care disciplines and specialities within those disciplines (Pearson and Williams 1972). The role played by those specialists will vary across specialists and within speciality from time to time. A necessary condition for coordinated care is understanding of the role each specialist is playing at a given time.

The two principle roles that a Medical professional plays are those of primary care or consultant. Bennett (1982) describes these two roles for the

pediatrician participating on a child development team. "For the majority of handicapped infants and children from birth to 3 years of age, the pediatrician will often be the most appropriate person to serve as community case manager, coordinating and synthesizing the child's total care. This is particularly true for the young child with complex, changing medical problems in addition to developmental delays (309.)" For older children, the primary role for the pediatrician will usually be a consultant to the team. The teacher or therapist will be the appropriate case manager in many such cases. Johnston and Magrab (1976) and Allen, Holm and Schiefelbush (1978) contain descriptions of primary case and consultation roles for most disciplines involved in interdisciplinary team evaluation and management of children with developmental disabilities. No matter who serves in the primary care role it is essential that that person share with the parents the responsibility for seeing that the student's overall health needs, and not just specialized treatments, are considered in the planning of interventions.

Suggested Guidelines

What the parent can and should request of medical personnel:

Before describing the specifics of what parents should be able to request of their child's primary physician and other medical personnel a note of caution is in order. The specifics identified represent an idealized situation. It seems unlikely that the experiences of particular parents will meet this ideal. The caveat to parents is this: identify the elements of this ideal that are missing in your situation and set priorities for changing the situation according to a combination of the following criteria. How important is this element to my short and long term goals for my child and my family? What is the probability of accomplishing the change? A specific example may help clarify the latter criterion. In the case of a given professional you

may not be able to establish the rapport you feel is essential for a parent-professional partnership. However, you may live in a location where that professional is the only specialist in your geographic area. Thus, you may not have the option of changing to another specialist and you may not wish to risk alienating that professional, a possible consequence of your effort to educate him or her regarding how he or she is offending you. A compromise such as this may be necessary in order to maintain the care your child needs. This example reflects poorly on the style and skills of some professionals. There is no reasonable justification and can be no acceptable apology for such a situation. It is, unfortunately, a realistic statement, and a situation about which anger is justified. The advice offered here is to select a "less risky" short term objective for your advocacy for your child and family.

Specific attitudes and assistance that you should expect from professionals include:

1. Acceptance of you, the parent, as a contributing partner in the management of your child's care.
2. Clarification of roles and responsibilities for yourself and for the professionals involved in your child's care.
3. Knowledge on the part of professionals of the resources available for your child, and you and your family.
4. Information regarding treatment options that are available; an explanation of the reasons for the professional's preference for a given option.
5. Opportunity for you, the parent, to participate in setting priorities for care.
6. Opportunity to ask questions of the professionals in an

unhurried and non- defensive atmosphere.

7. Professionals should be able to anticipate issues regarding your child's care before they become acute problems and should provide "anticipatory guidance" as a means of problem prevention.
8. You have the right to expert professionals who are informed regarding new developments in techniques of care for your child.
9. An atmosphere that places your child's needs over issues of professional territories.
10. Maintenance of support and help throughout your child's development; too often supports are withdrawn once the child becomes older and less "appealing."
11. Support and direction that allows for you, the parent, personal growth and increasing independence.
12. Every professional should reflect concern with your child as a whole being in the context of your family, even though his or her area might be highly specialized.

<u>The dilemma of coordinating services among specialities - what the parent can do.</u>

During the discussion at the conference a number of suggestions were made as to what parents might do. The following list of items relates to actions that will help coordination of medical care. This is only a partial listing but will, it is hoped, generate other ideas. Also, many of these suggestions will sound familiar, as they are expressed in various ways in the references cited in this chapter.

1. Keep records. As parents you are the major source for continuity in your child's care. During the course of your

child's development he or she will probably see many different professionals. It is very important that you keep thorough records of all of your child's care (Smith and Robinson, 1982).

2. Ask questions so that you understand the rationale for and specifics of any treatment.
3. Review any treatment direction with the professional to insure that you will be able to carry it out correctly.
4. Let the professionals know when you feel they have done things well, not just when they don't do things well.
5. Tell professionals when a given recommendation is unrealistic for your situation. Then jointly work on problem solving that will make it feasible.
6. Be realistic about your own and other family members needs for respite from day to day demands of the care of your handicapped child. Don't feel that to be a good parent you always have to deny your own needs.
7. Become an informed consumer of the services you and your child need.
8. Seek support from and provide support to other parents.

Conclusion

Legislation PL-142, which has opened educational opportunities for students with extensive special needs, is a landmark development in our treatment of students with severe handicapps. Particularly noteworthy is the emphasis upon education's responsibility to provide related services that are necessary to an appropriate educational program. In many places "related services" has been interpreted in the broadest possible manner, placing the

fields of education and medicine in relationships and partnerships that they have not experienced before. Each field has accommodations to make that are likely to be very difficult for some members of each profession. Such accommodations are essential if effective refinement of the "Education for all Handicapped" legislation is to realize its full potential.

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